

# Data Exchange Framework Roadmap

*Companion  
Document*

2025–2027



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# Table of Contents

- TABLE OF CONTENTS** **2**
- PURPOSE OF THIS DOCUMENT** **3**
- CROSS-PILLAR CONSIDERATIONS** **4**
- Privacy 4
- PILLAR #1 EVENT NOTIFICATION** **7**
- Landscape 7
- Issue To Be Addressed 10
- PILLAR #2 SOCIAL SERVICE DATA SHARING** **15**
- Landscape 15
- PILLAR #3 CONSENT MANAGEMENT** **18**
- Landscape 18
- PILLAR #4 PUBLIC HEALTH** **22**
- Issue To Be Addressed 22
- APPENDIX I. GLOSSARY OF ABBREVIATIONS** **26**

# Purpose of This Document

The purpose of the **Data Exchange Framework (DxF) Roadmap Companion Document** is to provide supplementary background on select components of the main DxF Roadmap document. The Companion Document includes additional content on DxF Roadmap priority areas and cross-pillar considerations (e.g., discussion of nationwide and state models for event notification, a review of relevant privacy law, etc.) as well as a glossary of terms. All recommendations and descriptions of actionable steps are included in the main DxF Roadmap document.

# Cross-Pillar Considerations



## Privacy

The legal framework governing data privacy in California is complex, shaped by various federal and state laws that protect individuals' privacy while enabling secure exchange of Health and Social Services Information (HSSI).

## Federal Laws

The Health Insurance Portability and Accountability Act (HIPAA) and its Privacy Rule set national standards for the protection of an individual's health information held by "covered entities"—generally health care providers and health plans<sup>1</sup>—and their "business associates"—entities that perform services on the behalf of covered entities that involve access to or use of protected health information (PHI). PHI is identifiable health information held by covered entities or business associates. The Privacy Rule requires that covered entities and their business associates implement privacy safeguards and limit the use and disclosure of PHI. HIPAA also grants individuals the right to access, correct, or direct the sharing of their data.

HIPAA permits data-sharing by covered entities—such as Medi-Cal managed care plans, behavioral health plans, providers, and health systems—for purposes of treatment, payment, and health care operations without an individual's authorization.<sup>2</sup> This data-sharing can be between HIPAA-covered entities, and disclosures by covered entities are also allowed to non-covered entities—such as housing providers—for purposes of treatment, care coordination, and care management.<sup>3</sup>

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1 U.S. Department of Health and Human Services. "The HIPAA Privacy Rule." September 27, 2024. <https://www.hhs.gov/hipaa/for-professionals/privacy/index.html>.

2 U.S. Department of Health and Human Services. "The HIPAA Privacy Rule." September 27, 2024. <https://www.hhs.gov/hipaa/for-professionals/privacy/index.html>.

3 45 C.F.R. § 164.502 ; U.S. Department of Health and Human Services. "FAQ 3008 Does HIPAA permit health care providers to share protected health information (PHI) about an individual with mental illness with a third party that is not a health care provider for continuity of care purposes?" June, 8, 2020. <https://www.hhs.gov/guidance/document/faq-3008-does-hipaa-permit-health-care-providers-share-protected-health-information-phi>.

Other federal laws provide targeted protections for specific types of HSSI. For example:

- Title 42 C.F.R. Part 2,<sup>4</sup> hereinafter referred to as Part 2, governs the confidentiality of substance use disorder (SUD) data held by certain SUD providers or programs. To be subject to Part 2, a provider or program must receive federal assistance; and hold itself out as providing SUD treatment, diagnosis, or referral services. When it applies, Part 2 is more restrictive than HIPAA in that it requires individual authorization for disclosures of SUD data even for purposes of treatment, payment, and care coordination. Recent updates to the Part 2 regulations have aligned the rule more closely with HIPAA, allowing individuals to provide broad consent for disclosures of their SUD data for treatment, payment and health care operations using a single form, to designate categories of recipients rather than individual recipients; and provide a consent expiration date of “none.”
- The Family Educational Rights and Privacy Act<sup>5</sup> (FERPA), which regulates access to student health and education records, requires the consent of a parent and guardian before health and social services information held by certain schools can be disclosed.
- The Individuals with Disabilities Education Act (IDEA)<sup>6</sup> contains additional confidentiality provisions for records of students with disabilities.
- HUD funded entities—in particular Continuums of Care (CoC)—must comply with HUD regulations and policies when sharing housing information, including providing a privacy notice to individuals that describes the ways in which the CoC will use and disclose their personal information in order to provide them with housing and other services.

## State Laws

In addition to these federal laws, HSSI in California is also protected by state health and social services privacy laws and regulations, which have their own confidentiality and consent requirements.

The Confidentiality of Medical Information Act (CMIA)<sup>7</sup> for the most part mirrors HIPAA, though it applies, through its definition of “provider of healthcare,” more broadly than HIPAA, and is more restrictive than HIPAA in certain respects. For example, the CMIA permits disclosures of medical information for treatment purposes to a more limited set of recipients than does HIPAA<sup>8</sup> and has more stringent requirements regarding disclosure authorization forms.<sup>9</sup> The CMIA also provides for both civil and criminal penalties for violations, while HIPAA only allows for civil penalties assessed by

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4 42 C.F.R. Part 2..

5 20 U.S.C. § 1232g.

6 20 U.S.C. § 1400.

7 California Civil Code § 56–56.37.

8 California Civil Code §§ 56.10(c)(1), 56.11.

9 California Civil Code § 56.11.

the federal Health and Human Services Department, Office for Civil Rights (OCR); the CMIA also sets higher maximum penalties than HIPAA for certain types of violations.<sup>10</sup>

With respect to sensitive data categories, California has a number of laws that create protections that go beyond HIPAA. For example:

- The Lanterman-Petris-Short Act<sup>11</sup> specifically protects the confidentiality of inpatient mental health data and allows the disclosure of such information, absent consent, only in limited circumstances that are more narrow than HIPAA.<sup>12</sup> The state's health and safety code protects the confidentiality of SUD information, similarly allowing disclosure of SUD records without authorization only in limited circumstances more narrow than HIPAA.<sup>13</sup>
- The health and safety code has specific protections for HIV test results, restricting disclosure in most circumstances without individual consent.<sup>14</sup>
- The health and safety code also ensures patients have a right to consent to certain disclosures of their health information, as well as to access information related to their own conditions and care.<sup>15</sup>

Importantly, to promote data sharing and care coordination, the California State legislature passed AB 133 in 2021 to ease state privacy restrictions in alignment with the goals of California Advancing and Innovating Medi-Cal (CalAIM) initiatives. This law permits the sharing of data among Medi-Cal partners for purposes of implementing CalAIM and preempts more restrictive state laws requiring individual consent to disclose certain information. This means that, generally, federal law and its consent requirements govern the exchange by Medi-Cal partners of HSSI in California when exchanging such data is for the purposes of implementing CalAIM.<sup>16</sup>

Given the complexity of state and federal laws and regulations, health care and social service organizations often struggle to navigate privacy requirements. The DxF Roadmap includes recommendations to develop standards, use cases and other educational materials to help stakeholders navigate privacy laws related to event notifications, social service data sharing, consent management, and public health.

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<sup>10</sup> California Civil Code § 56.36.

<sup>11</sup> California Welfare and Institutions Code. §§ 5328–5330.

<sup>12</sup> California Welfare and Institutions Code § 5328.

<sup>13</sup> California Health and Safety Code § 11845.5.

<sup>14</sup> California Health and Safety Code § 120980 and 121010.

<sup>15</sup> California Health and Safety Code § 123100–123149.5.

<sup>16</sup> California State Legislative. Assembly Bill 133, Chapter 143. 2021.

PILLAR #1

# Event Notification



## Landscape

### Summary of Current State

#### *Federal Requirements for Event Notification*

In 2020, the Centers for Medicare & Medicaid Services (CMS) established certain requirements in their 2020 Interoperability and Patient Access Final Rule for hospitals to send notifications of admissions to and discharges from a patient’s primary care provider (PCP) and other providers identified by the patient as part of Conditions of Participation in Medicare and Medicaid programs.<sup>17</sup> The Final Rule, however, does not establish clear technical standards or an architecture for reporting admissions and discharges. It also places the burden, and the opportunity, of identifying providers that should receive notifications on the patient, which often results in the exclusion of key members of the care continuum.

Unlike the CMS Final Rule, the DxF requires hospitals and emergency departments (EDs), and encourages skilled nursing facilities (SNFs), to send notifications of admissions and discharges to any authorized DxF Participant that requests them.<sup>18</sup> The DxF also established a mechanism for identifying recipients of notifications that differs from the CMS Final Rule by requiring DxF Participants to request notifications by submitting a roster containing the identities of individuals for which notifications were requested.

#### *Event Notification among QHIOS*

The DxF Qualified Health Information Organization (QHIO) Program requires QHIOS to exchange rosters; receive admission and discharge event messages from DxF Participant hospitals, EDs, and SNFs who are their customers; and send admission and discharge notifications to other QHIOS based on the rosters they exchange. Many QHIOS had an existing event notification service in place prior to becoming a QHIO. All the QHIOS that described their existing notification service to the state

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<sup>17</sup> “Medicare and Medicaid Programs; Patient Protection and Affordable Care Act; Interoperability and Patient Access for Medicare Advantage Organization and Medicaid Managed Care Plans, State Medicaid Agencies, CHIP Agencies and CHIP Managed Care Entities, Issuers of Qualified Health Plans on the Federally-Facilitated Exchanges, and Health Care Providers,” Fed. Reg. 85, Reg. 85, 1-131 (May 1, 2020).

<sup>18</sup> Technical Requirements for Exchange Policy and Procedure v1.0.1.

support rosters as the mechanism to request notifications, with many using that method exclusively.

Most QHIOs support several methods for “sending” notifications, including:

- Transmitting alerts into an electronic health record (EHR);
- Sending notifications via secure messaging or secure email;
- Listing notifications on a portal to which providers log in; or
- Sending lists of notifications on a regular basis via a fax gateway.

QHIOs are collaborating to develop a standard format and mechanism for exchanging rosters with other QHIOs. They agreed on a preference for exchanging events with other QHIOs via Health Level Seven (HL7) Admit, Discharge, and Transfer (ADT) messages. While the consensus standards QHIOs are voluntarily adopting provide useful input into the DxF, QHIO consensus standards are not required of other DxF Participants.

## *ADT Networks*

Stakeholders have long recognized that knowledge of admissions and discharges in acute care settings, especially from EDs, is an important component of coordinated care, improved outcomes, and lower health care costs. As a result, “private networks” comprising solutions to collect and communicate admissions to and discharges from acute care settings have appeared within California and elsewhere.

- As noted above, many QHIOs had an existing service to provide notifications of admissions and discharges within their service areas before they joined DxF and before becoming a QHIO. Most of these services were designed to alert providers of admissions and discharges of their patients to facilitate timely follow-up.
- Other nonprofit entities, including health information organizations or health information exchanges (HIEs) that are not QHIOs, likewise may have notification services similar to those reported by QHIOs. At least one HIO has created a statewide service for collecting and distributing ADTs that might facilitate notifications for DxF.
- Some for-profit organizations had existing notification services that might be statewide in geographic scope. These networks might be focused on providing better coordination among EDs to reduce ED admissions, and/or to provide plans with better awareness of the admissions and discharges of their plan members.

Unfortunately, in the absence of a common statewide approach in California, the existing models contribute to a patchwork of solutions, some of which don’t interoperate with others. The diversity of business models and purposes for which the networks were created also contributes to stakeholder uncertainty in how best to meet DxF obligations for notifications and how best to be informed of admissions and discharges.



## *Event Notification in Public Health*

In 2024, the California legislature passed SB159<sup>19</sup> which provides the California Department of Public Health (CDPH) with new legal authority to collect and require syndromic data submissions from hospitals with EDs. This legislation requires use of messaging standards published by the U.S. Centers for Disease Control and Prevention (CDC).<sup>20</sup> Hospitals with EDs are required to deidentify and report specific event types for all patients, not just for those found on a roster. This new requirement illustrates the growing interest in event notification for use cases beyond care coordination.

## *Other Nationwide and State Models for Event Notification*

The Massachusetts Health Information Highway (Mass HIway) established a statewide Event Notification Service<sup>21</sup> (ENS) to alert providers about their patients' admissions to and discharges from hospitals, EDs, and post-acute care facilities. Like California's DxF, providers on Mass HIway may subscribe to notifications of admissions and discharges based on a roster of patients. Unlike DxF, however, Mass HIway's ENS establishes a coordinated architecture wherein hospitals, EDs, and post-acute care facilities must send event messages to one of a small number (currently two) state-selected ENS vendors. Mass HIway's ENS vendors share messages with each other, process patient rosters, forward notifications to providers when matched to a roster, and discard the event if no match is found.

Patient Centered Data Home™<sup>22</sup> (PCDH) offers a different model for event notifications dependent upon a network of cooperating health information exchanges (HIEs), each serving a defined geography (i.e., a "patient's data home"). Within PCDH, a participating HIE checks the home ZIP code of the patient for which it receives an admission or discharge message. If that ZIP code is not served by that HIE, the HIE seeks to identify the HIE(s) that serve that ZIP code (if any) using PCDH's centralized directory and forwards the message to the so-identified HIE(s). If the recipient HIE recognizes the patient, it may act upon the message in several ways depending upon how it serves its clients:

- Saving the event as part of the longitudinal community record for the patient;
- Sending a notification of the admission or discharge to members of the patient's care team;

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19 California State Legislature. Senate Bill No. 159 (2023-2024).

20 Centers for Disease Control and Prevention. "PHIN Messaging Guide for Syndromic Surveillance: Emergency Department, Urgent Care, Inpatient and Ambulatory Care Settings." Accessed October 23, 2024. [https://www.cdc.gov/nssp/documents/guides/syndrsurvmessagguide2\\_messagingguide\\_phn.pdf](https://www.cdc.gov/nssp/documents/guides/syndrsurvmessagguide2_messagingguide_phn.pdf)

21 The Massachusetts Health Information Highway. "Statewide ENS Framework." Accessed October 23, 2024. [https://www.masshiway.net/Services/Statewide\\_ENS\\_Framework](https://www.masshiway.net/Services/Statewide_ENS_Framework)

22 Civitas Networks for Health: "Patient Centered Data Home." Accessed October 23, 2024. <https://www.civitasforhealth.org/wp-content/uploads/2022/08/Civitas-PCDH-Datasheet-2022-08-21.pdf>.

- Sending a return message to the sending HIE notifying it that health information on the patient may be available for exchange using other methods, such as a nationwide network; and/or
- Requesting additional information on the subject patient and event such as admission notes or a discharge summary, again using other methods such as a nationwide network.

PCDH does not depend upon rosters for sharing event notifications, but instead sends notifications to HIEs based on an assumption that an appropriate recipient can be identified based on service geography, and that the recipient may be authorized to receive and use the notification and will act upon it appropriately.

Some QHIOs intend to participate in PCDH. Some California stakeholders have expressed concern that sending notifications based solely on geographic service area may not properly respect patient privacy. Further, the PCDH approach violates the first tenet of this pillar by sending notifications to organizations that have not requested them.

Outside of PCDH, no nationwide network or framework—including eHealth Exchange, Carequality, CommonWell Health Alliance, or the Trusted Exchange Framework and Common Agreement (TEFCA)—provides a framework, an architecture, or technical standards for event notifications that DxF can leverage. Notifications of admissions and discharges are not yet being discussed as a capability of Qualified Health Information Networks (QHINs) or TEFCA, nor does it currently appear on any TEFCA roadmap.

In the absence of a nationwide network or framework for communicating notifications, DxF P&Ps<sup>23</sup> opted for flexibility in how event notifications are requested and delivered. DxF Participants that are hospitals, EDs, and SNFs are individually allowed to determine the method and format for submitting rosters, requiring only that rosters conform to DxF person-matching requirements.<sup>2</sup> DxF Participants that are hospitals, EDs, and SNFs are also individually allowed to determine the content and format of notifications they transmit, and the method for sending notifications. The lack of specific technical standards for event notification has led to confusion and administrative burden among DxF Participants.

## Issue To Be Addressed

### Issue Statement

California has no coordinated, statewide method for those providing health care and social services to remain informed of significant events impacting the health of those they serve, creating gaps in care coordination among health care providers, health plans, social services providers, and government agencies and missing opportunities to improve whole person health.

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<sup>23</sup> Technical Requirements for Exchange Policy and Procedure v1.0.1.

Three critical barriers to exchanging event notifications in California include the lack of common architecture, technical standards, and method for identity matching.

## *Issue #1: Lack of Common Architecture*

There is no overarching, common, statewide architecture for sending and receiving event notifications in California. DxF Participants and advisory group members have expressed a desire to use rosters to request notifications, consistent with the first tenet of this pillar. However, there is likewise no overarching, common, statewide architecture for collecting and processing rosters. The lack of a common architecture results in significant barriers and burdens for both those receiving and those sending notifications:

- Those wishing to receive notifications must submit rosters to hundreds of organizations, using different formats, requiring different content, and using different submissions methods;
- Those required to send notifications must receive and manage rosters from hundreds of organizations, with some rosters likely identifying millions of patients;
- Those required to send notifications must send them to many organizations; and
- Those receiving notifications will receive them from many organizations, in different formats, with different content, and using different exchange methods, including some methods that are inconvenient to integrate into their workflows.

Based on the current sample of DxF Participants entering their choices in the DxF Participant Directory, approximately half of hospitals have chosen not to use a QHIO to manage rosters or send notifications and approximately one in five ambulatory providers have not onboarded to a QHIO.<sup>24</sup> These statistics suggest that:

- All DxF intermediaries supporting notifications of admissions and discharges and at least 20% of ambulatory providers would be required to submit rosters to hundreds of hospitals, EDs, and SNFs in order to receive all potential notifications of admissions and discharges; and
- Half of hospitals would have to process rosters from hundreds of DxF Participants, setting up unique point-to-point connections to each one in order to communicate notifications.

The lack of a common, statewide architecture creates fragmentation and presents a potentially untenable burden on DxF Participants who are required to send and desire to receive event notifications across California. It also compounds the uncertainty regarding who may receive notifications containing PHI and how individuals consent or decline to consent to notifications regarding events that impact their health.

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<sup>24</sup> Statements are based on choices entered by one third of DxF Participants in the DxF Participant Directory for how they exchange Health and Social Services Information.

## *Issue #2: Lack of Common Technical Standards*

The DxF has leveraged the technical standards in use by nationwide networks and frameworks, notably including TEFCA, when establishing technical requirements for many exchange types. However, the DxF did not establish technical standards for communicating events or notifications due to a lack of national initiatives to leverage. The lack of specific technical standards in the DxF's event notification requirements increases the complexity and burden for:

- Those submitting rosters to many organizations using different formats and methods;
- Those receiving notifications from many organizations using different formats and methods; and
- Intermediaries that must support many technical standards and translate among them to meet their customers' capabilities to receive notifications.

For many providers without strong information technology support or sufficient administrative staff, the complexity and fragmentation created by the lack of standards puts submitting rosters and processing notifications out of reach.

## *Issue #3: Lack of a Common Individual/Patient Identity*

Organizations required to receive rosters and send notifications need to match the identities of individuals on a roster to the identities of individuals that are the subject of an event. The DxF Strategy for Digital Identities<sup>25</sup> established a common set of attributes to be used by DxF Participants to match identities of individuals within different systems and care settings. DxF Policies and Procedures established requirements to use these attributes, including for identities in rosters and transmitted events and notifications.

However, most DxF Participants have minimal access to sophisticated technologies capable of effective person matching. Estimates suggest that typical matching methods implemented in EHRs may identify as few as 30% of records belonging to an individual.<sup>26</sup> QHIOs utilize much more sophisticated matching technologies. However, some QHIOs have expressed that the cost of person matching using these technologies may be prohibitive on a statewide scale that includes very large rosters.

## **Opportunities for Resolution**

California could pursue several opportunities, as listed in the table below, to resolve the barriers to effective statewide event notification.

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25 Center for Data Insights and Innovation, California Health and Human Services Agency. "Strategy for Digital Identities." July 1, 2022.

26 Eric Heflin, Shan He, Kevin Isbell, et al, A Framework for Cross-Organizational Patient Identity Management (The Sequoia Project, 2018).

TABLE 1 Summary of Issues and Opportunities to Resolve Them

Issue	Opportunities
<b>Lack of Common Architecture</b>	<ul style="list-style-type: none"> <li>● Establish a structure for submitting, managing, and accessing rosters</li> <li>● Establish a structure for submitting events, matching them to rosters, and communicating notifications</li> <li>● Explore establishing shared or coordinated statewide services to promote efficiencies and lower administrative burden</li> </ul>
<b>Lack of Common Technical Standards</b>	<ul style="list-style-type: none"> <li>● Establish minimum required method for submitting rosters, which may differ depending on who is submitting a roster and to whom</li> <li>● Establish minimum technical standards for content and method of exchange by which DxF Participants communicate events to intermediaries</li> <li>● Establish minimum technical standards for content and method of exchange of notifications to DxF Participants that request them</li> <li>● Preserve technical options to avoid stifling innovation</li> </ul>
<b>Lack of Common Individual Identity</b>	<ul style="list-style-type: none"> <li>● Establish minimum technical standards for content and format for rosters</li> <li>● Collaborate with other Pillars to establish a common method of establishing individual identity on DxF</li> </ul>

Cross-enterprise information sharing in health care is dominated by query-based exchange—that is, an organization requests information from another organization in advance of, during, or following an encounter. Query-based exchange is supported on all nationwide networks and frameworks, including TEFCA, is the focus of most emerging technical standards such as Fast Healthcare Interoperability Resource (FHIR), and is required of all DxF Participants.

DxF stakeholders have called for an increase in push-based exchange (i.e., sending information to an organization rather than waiting for the organization to request it). This approach is thought to provide more timely and complete awareness of an individual’s health status. Push-based exchange is supported on nationwide networks and frameworks (although TEFCA has delayed implementation) but is seldom implemented or used by network/framework participants. Receipt of Health and Social Services Information by push-based exchange is optional for DxF Participants. Push-based exchange may lead to information overload, a common complaint of health care providers receiving unsolicited discharge summaries from hospitals implementing direct secure messaging as part of their compliance with Meaningful Use requirements. Push-based exchange may present a privacy concern for individuals who desire the ability to restrict the flow of their HHSI. Push-based exchange also violates the first tenet of this pillar to only send DxF Participants the Health and Social Services Information they request unless the exchange is in response to an order or referral that has been requested.

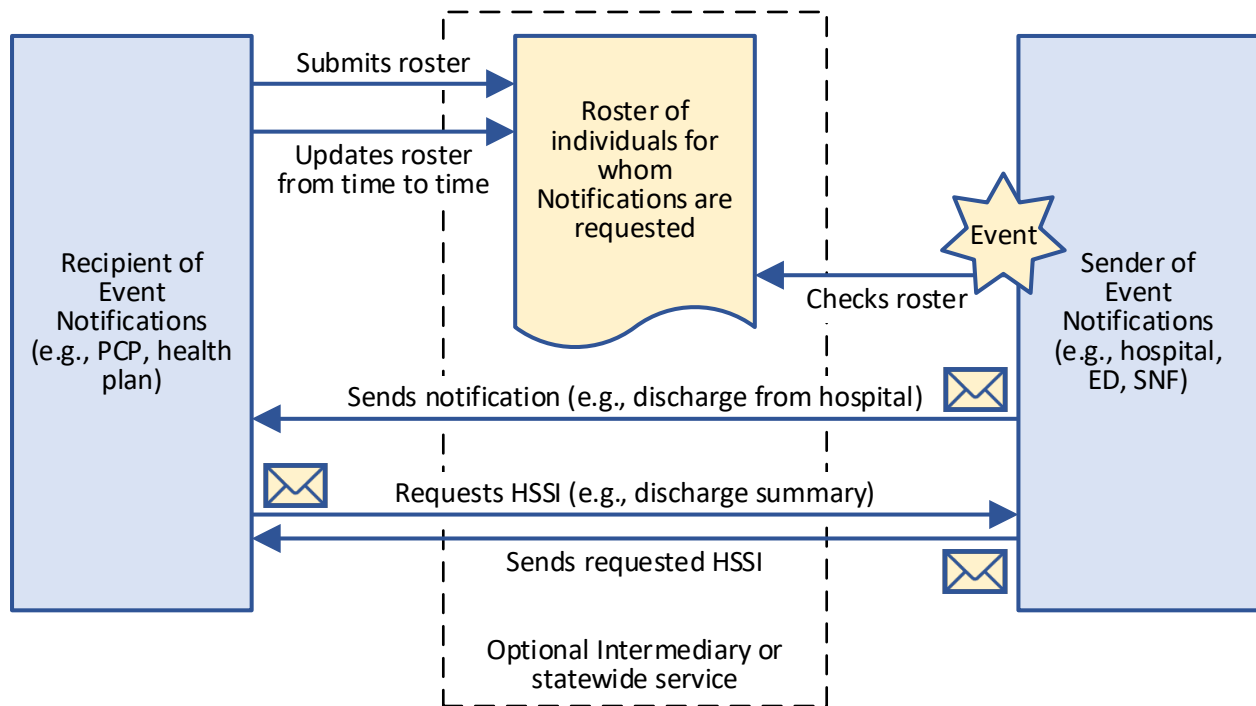
The event notification pillar recommends a new exchange type for standardized event notification to be known as “Event-Based Exchange.” Event-Based Exchange would support the notification of significant events that impact the health of an individual among health care and social service

organizations as requested by a DxF Participant and as allowed by applicable law and individual consent. In response to notification of an event, a DxF Participant may then choose whether to retrieve more information about the event through query-based exchange. While they do not support event notification, the query-based exchange capabilities of nationwide networks, including TEFCA, can be utilized to obtain more information about an event to supplement existing DxF query mechanisms.

DxF identified an initial use case in notifications of ADT Events: communicating admissions to and discharges from acute and subacute care facilities to PCPs, other providers, and health plans. This use case is already embodied in DxF Policies and Procedures as a required exchange type for some DxF Participants.

**FIGURE 1**

The process envisioned for Event-Based Exchange using the first use case for DxF as an example: submission of a roster, receipt of notification, and follow-up request for HSSI. Event-Based Exchange may take place between two DxF Participants, may use one or more intermediaries (such as a QHIO or, for query-based exchange, a nationwide network such as TEFCA), or utilize statewide shared services.



The event notification pillar includes recommendations to explore use of Event-Based Exchange to other use cases and other scenarios beyond admissions to and discharges from acute and subacute care facilities.

PILLAR #2

# Social Service Data Sharing



## Landscape

### Summary of Current State

#### *Social Services in California*

In California, social services span beyond state or federal government-funded programs and are often administered by a range of community-based organizations (CBOs) and nonprofit organizations (see examples in Table 2, please note this list is not exhaustive).

TABLE 2 Examples of Social Services Offered in California

Oversight	Service/Program	Description
California Department of Public Health (CDPH)	Women, Infants and Children (WIC)	Services provided through Local WIC agencies, county health departments, community health centers, and community-based, nonprofit organizations. <sup>27</sup>
California Department of Social Services (CDSS)	Foster Care Services	Administered by county child welfare agencies that provide administration and case management of children in the foster care system.
Department of Health Care Services (DHCS)	Behavioral Health Bridge Housing Program	Provides funding to county Behavioral Health Agencies, who often contract with a range of CBOs and mental health providers to provide temporary, safe housing and essential support for people transitioning from homelessness to permanent housing. <sup>28</sup>

27 California Department of Public Health. "Woman Infants, and Children (WIC), Local Agencies." Accessed October 23, 2024. <https://www.cdph.ca.gov/Programs/CFH/DWICSN/Pages/LocalAgencies.aspx>.

28 Behavioral Health Bridge Housing. "County Behavioral Health Agencies." Accessed October 23, 2024. <https://bridgehousing.buildingcalhhs.com/county-behavioral-health-agencies/>.



There is also a wide range of longstanding community-based systems, some with their own social service data sharing capabilities (mostly with their participating service providers) including, for example:

- **California 2-1-1:** Free telephone service operated by county-based entities to connect Californians to local community services. Regional 2-1-1 service providers establish and maintain a database of available services and relevant programs/agencies.<sup>29</sup>
- **Homeless Management Information System (HMIS):** The U.S. Department of Housing and Urban Development (HUD) funds 44 Continuums of Care (CoC) in California charged with assisting individuals and families experiencing homelessness. Each CoC is responsible for maintaining an HMIS, which is a local information system used to collect individual-level data on the provision of housing support services to individuals and families at risk of experiencing homelessness.<sup>30</sup>

These systems have been designed for different purposes such as program and financial accountability, local community benefit, service navigation, and care coordination for specific populations. Due to these differences, community systems have historically lacked the ability to interoperate effectively, thereby limiting their capacity to provide a comprehensive understanding of member needs.

## *Investments in Whole-Person Care*

California has made significant investments to advance whole person care, particularly through DHCS. For example:

- Through the CalAIM initiative, DHCS funds **Enhanced Care Management (ECM) and Community Supports** services which integrate both clinical and non-clinical elements of care for high-need Medi-Cal Members and offer cost-effective alternatives to traditional Medi-Cal services. DHCS also created the **Providing Access and Transforming Health (PATH) program**, a five-year, \$1.85 billion initiative to build up the capacity and infrastructure of on-the-ground partners, such as CBOs, hospitals, county agencies, tribes, and others. These participants are a part of the Medi-Cal delivery system, administered through managed care plans (MCPs), working to implement [Enhanced Care Management and Community Supports](#) and [Justice Involved](#) services under [CalAIM](#). As part of their Population Health Management program, DHCS also released [Closed-Loop Referral](#) requirements in December 2024 for MCPs to track, support, and monitor Member referrals. These requirements will go live on July 1, 2025, for ECM and Community Supports and will be expanded over time.

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29 California Public Utilities Commission. "2-1-1 Information Services." Accessed October 23, 2024. <https://www.cpuc.ca.gov/industries-and-topics/internet-and-phone/211-information-services>.

30 HMIS: Homeless Management Information System - HUD Exchange. "Homeless Management Information System." Accessed October 23, 2024. <https://www.hudexchange.info/programs/hmis/>.



- DHCS will build on CalAIM waiver activities and further expand access to behavioral health programs through the **Behavioral Health Transformation initiative** which implements Proposition 1.<sup>31</sup>
- DHCS executed a data sharing agreement that enables partner agencies—CDPH and CDSS—to share member-level eligibility and enrollment data across WIC, CalFRESH (California’s version of the federal Supplemental Nutrition Assistance Program/SNAP), and Medi-Cal to maximize enrollment across these critical public programs. DHCS is supporting MCPs by developing rosters of Medi-Cal members likely eligible but not yet enrolled in CalFRESH and WIC and providing those rosters to MCPs to conduct outreach.
- DHCS also proposed a local **WIC data sharing pilot program** that aims to maximize enrollment of eligible Medi-Cal children and families into CalFRESH and/or WIC through data sharing, targeted outreach, and improved coordination between MCPs and county agencies.

In addition to the DxF and to aid in the implementation of whole person care initiatives, the state has also developed related guidance around the sharing of health information, including:

- **State Health Information Guidance (SHIG)** created by CDII to clarify federal and state laws that affect disclosure and sharing of health information.
- **Data Sharing Authorization Guidance (DSAG) and accompanying toolkits** created by DHCS offer guidance around data privacy and sharing consent laws, regulations, and legal protections for individuals and organizations involved in delivering or overseeing health and social services to Medi-Cal members.

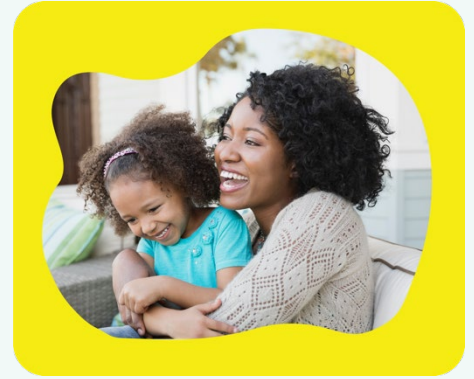
While these initiatives have made significant strides to further whole person care for the state’s Medi-Cal population, social service data sharing in California is still in early stages; even with DHCS data sharing contracting requirements with Medi-Cal plans. In addition, local data sharing efforts have not scaled broadly and are challenged with delivering timely information at points of service or contact with clients.

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<sup>31</sup> Proposition 1, a ballot initiative approved in 2024, aims to broaden the behavioral health continuum by offering targeted care to individuals with mental health conditions and substance use disorders, especially focusing on those who are most severely affected, vulnerable, or homeless.

PILLAR #3

# Consent Management



## Landscape

### Summary Of Current State

California's consent management landscape is complex and fragmented. Many organizations face challenges navigating complex rules and the various consent forms that may be used in jurisdictions to enable the exchange of protected HSSI.

For example, behavioral health providers often struggle to interpret and adhere to privacy regulations governing SUD data, as outlined in Part 2. This complexity leads many providers to default to not sharing SUD data with other organizations, even when it is legally permissible and could support better care coordination.

Additionally, few organizations treat changes to an individual's consent preferences as event notifications. Without standardized policies and procedures to notify health and social services organizations of an individual's modifications or revocations of consent, privacy risks increase as record and information sharing practices may not reflect the individual's most current preferences.

Moreover, consent management practices vary, with different systems in place across health and social service providers, including paper forms, as well as electronic systems such as EHRs, HIOs, and Community Information Exchanges (CIEs). Most QHIOs across the state do not currently have consent management capabilities, relying instead on providers and other organizations to manage consent processes.

Over the years, CalHHS, DHCS, and other state departments have developed guidance to help organizations comply with federal and state regulations around data privacy and sharing. CalHHS developed the SHIG<sup>32</sup>, which describes when certain HSSI can be exchanged, and provides clarity on state and federal privacy laws. In 2023, DHCS released the CalAIM DSAG<sup>33</sup> to provide guidance

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32 Center for Data Insights and Innovation, "State Health Information Guidance (SHIG)," April 2023. <https://www.cdii.ca.gov/compliance-and-policy/state-health-information-guidance-shig/>.

33 California Department of Health Care Services, "CalAIM Data Sharing Authorization Guidance," October 2023. <https://www.dhcs.ca.gov/CalAIM/ECM/Documents/CalAIM-Data-Sharing-Authorization-Guidance.pdf>.

to Medi-Cal Partners<sup>34</sup> who are providing or overseeing the delivery of health or social services to members. To complement the DSAG and SHIG, DHCS began developing DSAG Toolkits in 2024 to illustrate real world scenarios that help Medi-Cal Partners navigate data privacy and data sharing regulations related to CalAIM, including Assembly Bill 133 and the C.F.R. Part 2 Final Rule. The initial focus of these toolkits includes the Reentry Initiative, Medi-Cal Housing Support Services, and programs for Children and Youth. DHCS plans to make these toolkits available in 2025.

Additionally, DHCS piloted the Authorization to Share Confidential Medi-Cal Information (ASCMI) tools<sup>35</sup> in 2023 in San Diego, San Joaquin, and Santa Cruz counties to facilitate the exchange of protected HSSI about Medi-Cal members. The ASCMI tools used in the pilot included a standard release of information form and a regional consent management service designed to simplify the process of obtaining and managing consent to share protected Medi-Cal member data. The ASCMI form enabled Medi-Cal members to describe their preferences for sharing protected HSSI, which could be shared between counties, health plans, providers, and others via contracted HIO(s) and CIEs. This ensured that consent preferences were readily accessible to both the individuals and the health and social services organizations that serve them. The feedback from the pilot was promising, with many providers and individuals recommending broader implementation of the tools. As such, DHCS is in the process of refining the ASCMI tools, including enhancing the form based on feedback from pilot participants, and considering how they might support statewide consent management services.

Stewards of Change Institute (SOCl) recently published a conceptual model to address challenges in obtaining and managing consent to share information across health and human services. The SOCl white paper outlines various strategies for obtaining informed, voluntary consent from individuals to share their personal, identifiable, sensitive information across service providers, including the ASCMI tools as an example, to deliver whole person care.<sup>36</sup> The California Health Care Foundation also published a paper outlining the key components necessary to scale statewide consent services and implement a robust digital identity strategy.<sup>37</sup> By expanding the use of the ASCMI tools and learning from other models and experiences, California can establish scalable

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34 Medi-Cal Partner refers to any person or organization that provides Medi-Cal reimbursable health and social services to Members as a Medi-Cal Partner. This includes, but is not limited to, Medi-Cal MCPs, Tribal Health Programs, health care providers, community-based social and human services organizations and providers, local health jurisdictions, correctional facility health care providers, and county and other public agencies that provide services and manage care for individuals enrolled in Medi-Cal.

35 California Department of Health Care Services, "ASCMI CalAIM," 2023. <https://www.dhcs.ca.gov/CalAIM/Pages/ASCMI-CalAIM.aspx>.

36 Stewards of Change Institute, "Catalyzing Whole-Person Care: Consent-to-Share is the Key", September 23, 2024. [https://stewardsofchange.org/wp-content/uploads/sites/2/2024/09/SOCl\\_report.pdf](https://stewardsofchange.org/wp-content/uploads/sites/2/2024/09/SOCl_report.pdf).

37 California Health Care Foundation. Consent to Share: California's Approach to Cross-Sector Data Sharing. October 2023. <https://www.chcf.org/wp-content/uploads/2023/10/ConsentToShareCACrossSectorDataSharing.pdf>.

statewide consent management services that can be used by individuals, counties, managed care plans, providers, health systems, CBOs, and other government agencies.

At the federal level, several standards, specifications, and application programming interfaces (APIs) have been developed to support consent management including:

- *TEFCA*: Sets national standards for secure health information exchange between health information networks. The Common Agreement Version 2.0 released in April 2024, includes consent management requirements such as standardized processes for obtaining and managing individual consent for data sharing. The Common Agreement also includes requirements for written policies and procedures to allow an individual to change or revoke their consent on a prospective basis.<sup>38</sup>
- *Health Level Seven (HL7) Composite Privacy Consent Directive—domain analysis model*: Harmonizes security and privacy requirements in health care, aligning with international securities standards. The model focuses on implementing controls to enforce privacy policies, consent directives, and access standards across EHRs.<sup>39</sup>
- *HL7 Healthcare Privacy and Security Classification System, Release 1*: Outlines standards for automated labeling and segmentation of PHI, enabling health care organizations to manage patient consent and ensure that only authorized users can access protected data.<sup>40</sup>
- *HL7 Services Functional Model: Consent Management Service, Release 1*: Outlines standards on APIs for managing patient consent, enabling health care organizations to integrate consent management services into their systems.<sup>41</sup>
- *HL7 Clinical Document Architecture (CDA) R2 Implementation Guide: Privacy Consent Directives, Release 1*: Outlines standards on exchanging signed consent directives, enabling health care organizations to manage and enforce computable privacy consents across EHR systems while supporting multiple representations (e.g., narrative, signed and computable formats).<sup>42</sup>

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38 Office of the National Coordinator for Health Information Technology (ONC). "Trusted Exchange Framework and Common Agreement (TEFCA)." August 1, 2024.

<https://www.healthit.gov/topic/interoperability/policy/trusted-exchange-framework-and-common-agreement-tefca>.

39 Health Level Seven International (HL7). "HL7 Version 3 Domain Analysis Model: Composite Security and Privacy, Release 1," May 1, 2014.

[https://www.hl7.org/v3ballotarchive/v3ballot/html/dams/uvsec/V3DAM\\_SECURITY\\_R1\\_I1\\_2014MAY.pdf](https://www.hl7.org/v3ballotarchive/v3ballot/html/dams/uvsec/V3DAM_SECURITY_R1_I1_2014MAY.pdf).

40 Health Level Seven International (HL7). "HL7 Healthcare Privacy and Security Classification System (HCS), Release 1" August 8, 2014. [https://www.hl7.org/implement/standards/product\\_brief.cfm?product\\_id=345](https://www.hl7.org/implement/standards/product_brief.cfm?product_id=345).

41 Health Level Seven International (HL7). "HL7 Services Functional Model: Consent Management Service, Release 1," July 13, 2021. [https://www.hl7.org/implement/standards/product\\_brief.cfm?product\\_id=571](https://www.hl7.org/implement/standards/product_brief.cfm?product_id=571).

42 Health Level Seven International (HL7). "HL7 CDA® R2 Implementation Guide: Privacy Consent Directives, Release 1," December 9, 2021. [https://www.hl7.org/implement/standards/product\\_brief.cfm?product\\_id=280](https://www.hl7.org/implement/standards/product_brief.cfm?product_id=280).

- *HL7 Fast Health care Interoperability Resource (FHIR) Consent Resource*: Outlines a standard data model to represent and manage a patient's consent regarding the use, sharing and disclosure of their health care information.<sup>43</sup>
- *Integrating the Health care Enterprise (IHE) Basic Patient Privacy Consents*: Outlines standards for health care systems to record and enforce patient privacy consents, allowing flexibility in who can access health information based on the patient's consent.<sup>44</sup>
- *IHE Privacy Consent on FHIR*: Outlines standards for patient privacy consents and access control where a FHIR API is used to access document sharing health information exchanges.<sup>45</sup>

As the DxF continues to refine the framework for consent management, these federal standards provide a foundation for the development of interoperable, secure systems that safeguard patient privacy while promoting data sharing.

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43 HL7 Fast Healthcare Interoperability Resource (FHIR), "Resource Consent – Content," March 26, 2023. <https://www.hl7.org/fhir/consent.html>.

44 Integrating the Healthcare Enterprise (IHE). "Basic Patient Privacy Consents (BPPC)" August 4, 2023. <https://profiles.ihe.net/ITI/TF/Volume1/ch-19.html>.

45 Integrating the Healthcare Enterprise (IHE). "Privacy Consent on FHIR " February 23, 2024. <https://profiles.ihe.net/ITI/PCF/>.

## PILLAR #4

# Public Health



## Issue To Be Addressed

The existing fragmentation in California's public health data systems and funding structure complicate efforts to standardize data sharing across different public health reporting requirements and systems. The absence of a unified approach and common technical standards is leading to inefficiencies and large public resource demands to draw connections between and make modifications to individualized systems of record. Existing CDC/national infrastructures, such as those related to electronic case reporting and syndromic surveillance, are ripe for broader adoption and can be a starting point.

## Opportunities for Resolution

California's public health data systems, while currently siloed, present significant opportunities for enhanced interoperability through the potential roles of DxF and TECCA in supporting public health data exchange.

The DxF establishes Policies and Procedures for the secure exchange of HSSI for DxF Participants across many sectors, some of which may be implicated by a multitude of public health reporting requirements, standards, and electronic data systems that exist outside of the DxF. There is an opportunity for DxF to expand its guidance to incorporate public health standards and technical requirements to support greater ease and efficiency in data sharing and the adoption of interoperable data systems.

There are also opportunities for DxF to support partnering state and federal public health agencies (PHAs), such as CDC, CDPH, and local health jurisdictions (LHJs), in advancing interoperable exchange through discrete public health use cases. For instance, DxF could play a role in streamlining electronic case reporting and follow-up investigations or aligning with ED syndromic surveillance reporting requirements. Successfully addressing these use cases will require clear definitions of QHIO (DxF) versus QHIN (TECCA) roles in effectively supporting specific public health functions. While the most common challenges cited are resources needed for new systems, modifications, and connections, an overall move to common ontologies, languages and API exchange could yield significant economies of scale and effort. Use cases will need to address any state and/or local data sharing constraints as they apply to public health. Although CDII will not



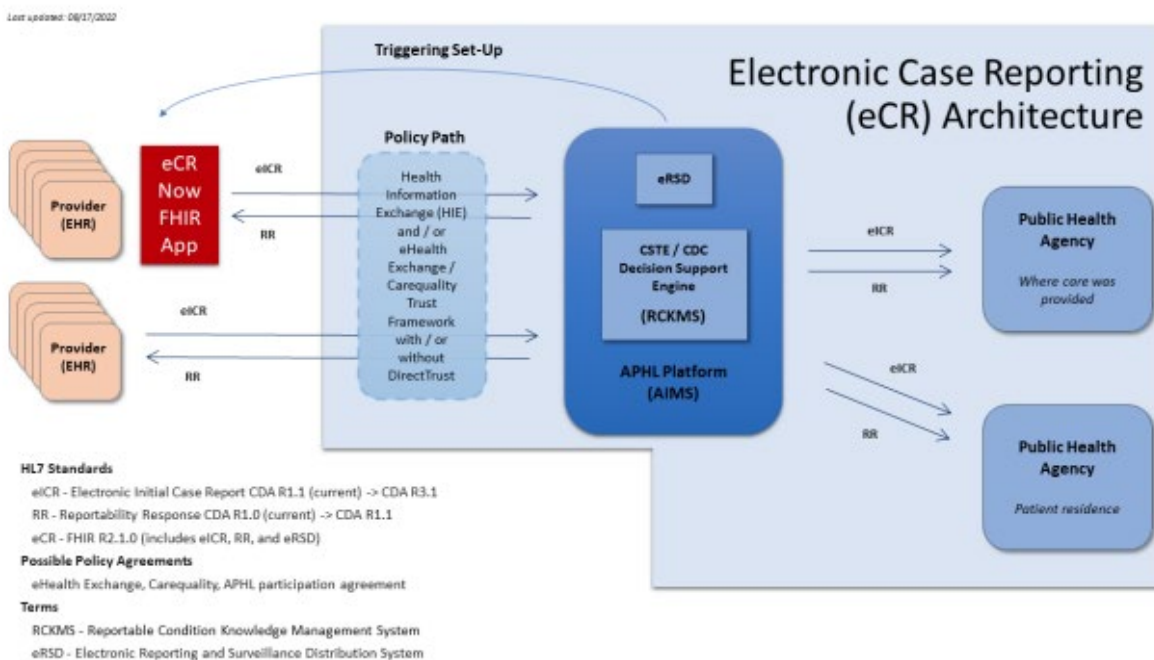
oversee the allocation of funds for the implementation of use cases, it will play a supportive role in advocating for funding to support these efforts.

## Scenarios/Use Cases

### 1. Implementation of eICR through TEFCA

Electronic Case Reporting (eCR) is the automated, near real-time generation and transmission of case reports from EHRs to PHAs for review and action.<sup>46</sup> Health care providers are required by law to report diseases and conditions of interest to public health throughout the United States and its territories. The eCR platform, the Association of Public Health Laboratories' (APHL) Informatics Messaging Services (AIMS), directly connects to clinical providers via their EHRs and electronically flows case reporting information to California public health entities. In some cases, data flows directly to an LHJ (such as Los Angeles County) and for other jurisdictions the data flows through the CalREDIE platform to the LHJs. CDPH maintains the direct connection between AIMS and CalREDIE. CDC's eCR team, in coordination with APHL and the Council of State and Territorial Epidemiologists, provides support for eCR implementers, with state or local PHAs responsible for setting data reporting requirements and assuring data quality for reporting purposes.

FIGURE 2 Electronic Case Reporting Architecture via AIMS. Graphic from 'Introduction to eCR—For EHR and Health IT Vendors.'



46 Centers for Disease Control and Prevention. "Electronic Case Reporting (eCR)." Accessed October 21, 2024. <https://www.cdc.gov/ecr/php/index.html>.

The electronic initial case report, or eICR, is triggered locally in the EHR system and sent to the AIMS platform. In some circumstances, the eICR will be all that is needed to support public health reporting. Having electronic case reports on reportable conditions sent from EHRs and received by PHAs represents a significant accomplishment of interoperability between health care and public health. The eICR may lead to the reporting of additional data or follow-up by the PHA to: confirm reportability; provide condition-specific or public health jurisdiction-specific case data; and/or support public health investigation, contact tracing, and/or countermeasure administration. The eICR is a HL7 CDA balloted standard for reporting to public health.

One of the challenges noted by larger health care delivery systems that operate across geographies in California has been slightly different eICR reporting requirements by LHJs. This makes implementation more difficult, especially when adjustments need to be made by the EHR vendor in response. As part of the move to a national trusted framework (TEFCA) for data exchange, the Assistant Secretary for Technology Policy and Office of the National Coordinator for Health Information Technology (ASTP/ONC) has been working with the CDC to further modernize eICR and align with emerging FHIR data standards. In partnership with a large California provider-based organization, their EHR vendor, and its associated QHIN, they plan to implement eICR via TEFCA in California and further determine whether TEFCA can support the additional data information needs required for some reportable conditions. Similarly, DxF may provide the permissions and mechanism for public health queries and responses for that information.

As part of California's early implementation, CDPH will work to align consistent clinical data element requirements by reportable condition across LHJs and centralize effort at the state CDPH level rather than requiring effort with each LHJ across the state to support AIMS connectivity (efficiency + scale). This early implementation will also provide a glide path for broader eICR adoption across other QHIN participants in California.

### **What We Will Learn**

The DxF Data Sharing Agreement (DSA) and the TEFCA Common Agreement, while meant to be inclusive of public health use cases, were not specifically designed to support them. Early implementation will clarify if/how TEFCA can support LHJs in case reporting and management. It is unclear, for example, whether LHJs and/or CDPH will need to sign a TEFCA Common Agreement and, if so, whether as a participant or subparticipant.

Early implementation will help determine: whether LHJs can and should sign the DxF DSA for query/response access to clinical records; whether their DxF conditions of participation should differ from other DxF Participants; whether LHJ systems of record should be a part of this ecosystem; and further clarify how DxF aligns with CDC-funded CDPH and LHJ data modernization efforts and timelines.



## *2. Syndromic Surveillance Supported by DxF*

Alignment across DxF event notification requirements and ED syndromic surveillance reporting may markedly enhance participation given the common need for acute hospital ED ADT connectivity and strategies to assure statewide coverage and ability to route alerts across DxF Participants.

This use case differs in several key ways from other person-centered data exchanges. First, data reported to a national system is de-identified. Second, data sharing and reporting follows an HL7 message standard which is currently not a part of DxF event alert requirements. Third, given that DxF is now defining data flows to support event notifications, it is unclear whether this use case can and should be incorporated into the DxF.

### **What Needs To Be Done**

California is at an inflection point with its syndromic surveillance program—the recent passage of SB159, Chapter 40, Statutes of 2024, activates a direct role for CDPH (prior, engagement in syndromic surveillance was mediated by LHJs).

Further investigation is needed to determine what, if any, actionable steps can be taken by DxF in support of this use case. CDII and CDPH intend to delve further into understanding how the two programs might interact and ideally whether we can simplify engagement in both programs for acute care hospital EDs. The intent is to have a clear sense of actionable steps by quarter two of 2025.

Over the next three years, the CDC and ASTP/ONC will continue to generate joint use cases and initiatives using electronic data exchange to promote public health. These initiatives are developing rapidly and will drive DxF public health roadmap efforts in the next three years. Ideally, California will participate in early implementations, as well as help drive interoperability standard development and adoption aligned with federal priorities and investments.

# Appendix I. Glossary of Abbreviations

Abbreviation	Definition
ADT	admit (or admission), discharge, and transfer
AIMS	Association of Public Health Laboratories' (APHL) Informatics Messaging Services
APHL	Association of Public Health Laboratories
API	application programming interface
ASCOMI	Authorization to Share Confidential Medi-Cal Information
ASTP/ONC	Assistant Secretary for Technology Policy/Office of the National Coordinator for Health Information Technology
BHCIP	Behavioral Health Continuum Infrastructure Program
CalAIM	California Advancing and Innovating Medi-Cal
CalHHS	California Health & Human Services Agency
CalREDIE	California Reportable Disease Information Exchange
CBO	community-based organization
CDA	Clinical Document Architecture
CDC	U.S. Centers for Disease Control and Prevention
CDII	Center for Data Insights and Innovation
CDPH	California Department of Public Health
CDSS	California Department of Social Services
CDT	California Department of Technology
CIE	community information exchange
CMIA	Confidentiality of Medical Information Act
CMS	Centers for Medicare & Medicaid Services

Abbreviation	Definition
CoC	Continuums of Care
CYBHI	Children and Youth Behavioral Health Initiative
DHCS	(California) Department of Health Care Services
DSA	Data Sharing Agreement
DSAG	Data Sharing Authorization Guidance
DxF	<a href="#">Data Exchange Framework</a>
ECM	Enhanced Care Management
eCR	electronic case reporting
ED	emergency department
EHR	electronic health record
ENS	Event Notification Service
FERPA	Family Educational Rights and Privacy Act
FFP	Federal Financial Participation
FHIR	Fast Healthcare Interoperability Resources
FoPH	Future of Public Health
HIE	health information exchange
HIO	health information organization
HIPAA	Health Insurance Portability and Accountability Act
HL7	Health Level Seven
HMIS	Homeless Management Information System
HSC	Health and Safety Code
HSSI	Health and Social Services Information
HTI	Health Data, Technology, and Interoperability

<b>Abbreviation</b>	<b>Definition</b>
HUD	U.S. Department of Housing and Urban Development
IAC	Implementation Advisory Committee
IDEA	Individuals with Disabilities Education Act
IGA	Identity Governance and Administration
IHE	Integrating the Healthcare Enterprise
LHJ	local health jurisdiction
Mass Hlway	Massachusetts Health Information Highway
MCP	managed care plan
MPI	master patient index
OTSI	Office of Technology and Solutions Integration
P&P	(Data Exchange Framework) Policy & Procedure
PATH	Providing Access and Transforming Health
PCDH	Patient Centered Data Home™
PCP	primary care provider
PD	Participant Directory
PHA	public health agency
PHI	protected health information
POMGs	physician organizations and medical groups
QHIN	Qualified Health Information Network
QHIO	Qualified Health Information Organization
ReaLD	race, ethnicity and language, disability
RFIs	requests for information
RFP	request for proposals

Abbreviation	Definition
SDOH	social determinants of health
SHIG	State Health Information Guidance
SNAP	Supplemental Nutrition Assistance Program
SNF	skilled nursing facility
SOCi	Stewards of Change Institute
SOGI	sexual orientation and gender identity
SUD	substance use disorder
TEFCA	Trusted Exchange Framework and Common Agreement
USCDI+	United States Core Data for Interoperability Plus
WIC	Women, Infants and Children